

1 AN ACT concerning public health.

2 **Be it enacted by the People of the State of Illinois,**  
3 **represented in the General Assembly:**

4 Section 1. Short title. This Act may be cited as the  
5 Genetic and Metabolic Diseases Advisory Committee Act.

6 Section 5. Genetic and Metabolic Diseases Advisory  
7 Committee.

8 (a) The Director of Public Health shall create the Genetic  
9 and Metabolic Diseases Advisory Committee to advise the  
10 Department of Public Health regarding issues relevant to  
11 newborn screenings of metabolic diseases.

12 (b) The purposes of the Genetic and Metabolic Diseases  
13 Advisory Committee are all of the following:

14 (1) Advise the Department regarding issues relevant to  
15 its Genetics Program.

16 (2) Advise the Department regarding optimal laboratory  
17 methodologies for screening of the targeted conditions.

18 (3) Recommend to the Department consultants who are  
19 qualified to diagnose a condition detected by screening,  
20 provide management of care, and genetic counseling for the  
21 family.

22 (4) Monitor the incidence of each condition for which  
23 newborn screening is done, evaluate the effects of

1 treatment and genetic counseling, and provide advice on  
2 disorders to be included in newborn screening panel.

3 (5) Advise the Department on educational programs for  
4 professionals and the general public.

5 (6) Advise the Department on new developments and areas  
6 of interest in relation to the Genetics Program.

7 (7) Any other matter deemed appropriate by the  
8 Committee and the Director.

9 (c) The Committee shall consist of 20 members appointed by  
10 the Director of Public Health and approved by the Governor.  
11 Membership shall include physicians, geneticists, nurses,  
12 nutritionists, and other allied health professionals, as well  
13 as patients and parents. The term of membership shall be up to  
14 3 years. A member may be appointed for 2 consecutive terms.  
15 After 2 terms, a member must be off the Committee for a least  
16 one year. Members of the Committee must serve on a subcommittee  
17 or a special project. Ex-officio members may be appointed and  
18 may include the following:

19 (1) The Chief of the Division of Children's Health and  
20 Safety.

21 (2) The Director of the Division of Specialized Care  
22 for Children.

23 (3) The Administrator of the Genetics Program.

24 (4) The Chief of the Metabolic Section of the Division  
25 of Laboratories.

26 (5) The President of the Genetics Task Force of

1 Illinois, Inc.

2 (6) Representation from patient and parent support or  
3 advocacy groups.

4 Ex-officio members shall not have voting privileges.

5 Section 10. The State Finance Act is amended by changing  
6 Section 8h as follows:

7 (30 ILCS 105/8h)

8 Sec. 8h. Transfers to General Revenue Fund.

9 (a) Except as otherwise provided in this Section and  
10 Section 8n of this Act, and ~~(e), (d), or (e)~~, notwithstanding  
11 any other State law to the contrary, the Governor may, through  
12 June 30, 2007, from time to time direct the State Treasurer and  
13 Comptroller to transfer a specified sum from any fund held by  
14 the State Treasurer to the General Revenue Fund in order to  
15 help defray the State's operating costs for the fiscal year.  
16 The total transfer under this Section from any fund in any  
17 fiscal year shall not exceed the lesser of (i) 8% of the  
18 revenues to be deposited into the fund during that fiscal year  
19 or (ii) an amount that leaves a remaining fund balance of 25%  
20 of the July 1 fund balance of that fiscal year. In fiscal year  
21 2005 only, prior to calculating the July 1, 2004 final  
22 balances, the Governor may calculate and direct the State  
23 Treasurer with the Comptroller to transfer additional amounts  
24 determined by applying the formula authorized in Public Act

1 93-839 to the funds balances on July 1, 2003. No transfer may  
2 be made from a fund under this Section that would have the  
3 effect of reducing the available balance in the fund to an  
4 amount less than the amount remaining unexpended and unreserved  
5 from the total appropriation from that fund estimated to be  
6 expended for that fiscal year. This Section does not apply to  
7 any funds that are restricted by federal law to a specific use,  
8 to any funds in the Motor Fuel Tax Fund, the Intercity  
9 Passenger Rail Fund, the Hospital Provider Fund, the Medicaid  
10 Provider Relief Fund, the Teacher Health Insurance Security  
11 Fund, the Reviewing Court Alternative Dispute Resolution Fund,  
12 the Voters' Guide Fund, the Foreign Language Interpreter Fund,  
13 the Lawyers' Assistance Program Fund, the Supreme Court Federal  
14 Projects Fund, the Supreme Court Special State Projects Fund,  
15 the Supplemental Low-Income Energy Assistance Fund, the Good  
16 Samaritan Energy Trust Fund, the Low-Level Radioactive Waste  
17 Facility Development and Operation Fund, the Horse Racing  
18 Equity Trust Fund, the Metabolic Screening and Treatment Fund,  
19 or the Hospital Basic Services Preservation Fund, or to any  
20 funds to which subsection (f) of Section 20-40 of the Nursing  
21 and Advanced Practice Nursing Act applies. No transfers may be  
22 made under this Section from the Pet Population Control Fund.  
23 Notwithstanding any other provision of this Section, for fiscal  
24 year 2004, the total transfer under this Section from the Road  
25 Fund or the State Construction Account Fund shall not exceed  
26 the lesser of (i) 5% of the revenues to be deposited into the

1 fund during that fiscal year or (ii) 25% of the beginning  
2 balance in the fund. For fiscal year 2005 through fiscal year  
3 2007, no amounts may be transferred under this Section from the  
4 Road Fund, the State Construction Account Fund, the Criminal  
5 Justice Information Systems Trust Fund, the Wireless Service  
6 Emergency Fund, or the Mandatory Arbitration Fund.

7 In determining the available balance in a fund, the  
8 Governor may include receipts, transfers into the fund, and  
9 other resources anticipated to be available in the fund in that  
10 fiscal year.

11 The State Treasurer and Comptroller shall transfer the  
12 amounts designated under this Section as soon as may be  
13 practicable after receiving the direction to transfer from the  
14 Governor.

15 (a-5) Transfers directed to be made under this Section on  
16 or before February 28, 2006 that are still pending on May 19,  
17 2006 (the effective date of Public Act 94-774) ~~this amendatory~~  
18 ~~Act of the 94th General Assembly~~ shall be redirected as  
19 provided in Section 8n of this Act.

20 (b) This Section does not apply to: (i) the Ticket For The  
21 Cure Fund; (ii) any fund established under the Community Senior  
22 Services and Resources Act; or (iii) on or after January 1,  
23 2006 (the effective date of Public Act 94-511), the Child Labor  
24 and Day and Temporary Labor Enforcement Fund.

25 (c) This Section does not apply to the Demutualization  
26 Trust Fund established under the Uniform Disposition of

1 Unclaimed Property Act.

2 (d) This Section does not apply to moneys set aside in the  
3 Illinois State Podiatric Disciplinary Fund for podiatric  
4 scholarships and residency programs under the Podiatric  
5 Scholarship and Residency Act.

6 (e) Subsection (a) does not apply to, and no transfer may  
7 be made under this Section from, the Pension Stabilization  
8 Fund.

9 (Source: P.A. 93-32, eff. 6-20-03; 93-659, eff. 2-3-04; 93-674,  
10 eff. 6-10-04; 93-714, eff. 7-12-04; 93-801, eff. 7-22-04;  
11 93-839, eff. 7-30-04; 93-1054, eff. 11-18-04; 93-1067, eff.  
12 1-15-05; 94-91, eff. 7-1-05; 94-120, eff. 7-6-05; 94-511, eff.  
13 1-1-06; 94-535, eff. 8-10-05; 94-639, eff. 8-22-05; 94-645,  
14 eff. 8-22-05; 94-648, eff. 1-1-06; 94-686, eff. 11-2-05;  
15 94-691, eff. 11-2-05; 94-726, eff. 1-20-06; 94-773, eff.  
16 5-18-06; 94-774, eff. 5-19-06; 94-804, eff. 5-26-06; 94-839,  
17 eff. 6-6-06; revised 6-19-06.)

18 Section 15. The Phenylketonuria Testing Act is amended by  
19 changing Section 2 as follows:

20 (410 ILCS 240/2) (from Ch. 111 1/2, par. 4904)

21 Sec. 2. The Department of Public Health shall administer  
22 the provisions of this Act and shall:

23 (a) Institute and carry on an intensive educational program  
24 among physicians, hospitals, public health nurses and the

1 public concerning the diseases phenylketonuria,  
2 hypothyroidism, galactosemia and other metabolic diseases.  
3 This educational program shall include information about the  
4 nature of the diseases and examinations for the detection of  
5 the diseases in early infancy in order that measures may be  
6 taken to prevent the mental retardation resulting from the  
7 diseases.

8 (a-5) Beginning July 1, 2002, provide all newborns with  
9 expanded screening tests for the presence of genetic,  
10 endocrine, or other metabolic disorders, including  
11 phenylketonuria, galactosemia, hypothyroidism, congenital  
12 adrenal hyperplasia, biotinidase deficiency, and sickling  
13 disorders, as well as other amino acid disorders, organic acid  
14 disorders, fatty acid oxidation disorders, and other  
15 abnormalities detectable through the use of a tandem mass  
16 spectrometer. Beginning 6 months following the registration of  
17 the necessary reagents with the federal Food and Drug  
18 Administration and the Centers for Disease Control and  
19 Prevention has available quality assurance testing methodology  
20 for these processes, provide all newborns with expanded  
21 screening tests for the presence of Lysosomal Storage Disorders  
22 known as Krabbe, Pompe, Gaucher, Fabry, and Niemann-Pick. If by  
23 July 1, 2002, the Department is unable to provide expanded  
24 screening using the State Laboratory, it shall temporarily  
25 provide such screening through an accredited laboratory  
26 selected by the Department until the Department has the

1 capacity to provide screening through the State Laboratory. If  
2 expanded screening is provided on a temporary basis through an  
3 accredited laboratory, the Department shall substitute the fee  
4 charged by the accredited laboratory, plus a 5% surcharge for  
5 documentation and handling, for the fee authorized in  
6 subsection (e) of this Section.

7 (b) Maintain a registry of cases including information of  
8 importance for the purpose of follow-up services to prevent  
9 mental retardation.

10 (c) Supply the necessary treatment product where  
11 practicable for diagnosed cases for as long as medically  
12 indicated, when the product is not available through other  
13 State agencies.

14 (d) Arrange for or provide public health nursing, nutrition  
15 and social services and clinical consultation as indicated.

16 (e) Require that all specimens collected pursuant to this  
17 Act or the rules and regulations promulgated hereunder be  
18 submitted for testing to the nearest Department of Public  
19 Health laboratory designated to perform such tests. The  
20 Department may develop a reasonable fee structure and may levy  
21 fees according to such structure to cover the cost of providing  
22 this testing service. Fees collected from the provision of this  
23 testing service shall be placed in a special fund in the State  
24 Treasury, hereafter known as the Metabolic Screening and  
25 Treatment Fund. Other State and federal funds for expenses  
26 related to metabolic screening, follow-up and treatment

1 programs may also be placed in such Fund. Moneys shall be  
2 appropriated from such Fund to the Department of Public Health  
3 solely for the purposes of providing metabolic screening,  
4 follow-up and treatment programs. Nothing in this Act shall be  
5 construed to prohibit any licensed medical facility from  
6 collecting additional specimens for testing for metabolic or  
7 neonatal diseases or any other diseases or conditions, as it  
8 deems fit. Any person violating the provisions of this  
9 subsection (e) is guilty of a petty offense.

10 (Source: P.A. 92-701, eff. 7-19-02.)

11 Section 99. Effective date. This Act takes effect upon  
12 becoming law.